

Appendix 1: Ethnic categories

As a team, we did a considerable amount of research around the way that data are categorised by ethnicity. We are aware that the language and terminology to do with characterising ethnic groups can be sensitive, due, in part, to the close tie-in to individual and group identity. We would welcome any feedback and suggestions that you may have at: info@trialforge.org

Both 'race' and 'ethnicity' are social constructs. Governments and institutions around the world tend to make use of one or both terms (or, when not in English, similar notions), for example, in census questions. The concept of 'race' is controversial. The biological concept of race, whereby human populations are divided into sub-categories mainly based on visible physical characteristics, was dominant from the early 19th century. Modern ideas of race focus on social origins rather than biology. Even in this conception, race is based on physical and hence biological factors. We disagree with this perspective and, therefore, do not use the term 'race' in our work.

Ethnicity differs from race, nationality, religion, and migrant status, sometimes in subtle ways, but may include facets of these other concepts. It has been suggested that researchers who wish to study ethnicity should collect data on factors such as language, religion, country of birth, and family origins.

We also do not use the acronyms BME (Black and Minority Ethnic) and BAME (Black, Asian and Minority Ethnic), as informed by recent research findings and discussions. For example, a UK survey conducted in 2019 with almost 300 people found that very few people recognised the acronyms and only one knew vaguely what the acronyms stood for. As people have grown dissatisfied or expressed discomfort with the terms BME and BAME, there has been a move to instead use the term 'People of Colour' (PoC). However, white minorities, such as Romani or Irish travellers, are marginalised groups not included under the PoC umbrella. Therefore, the term may exclude some minority groups or individuals within those groups who should be included. Rather than focus on umbrella terms, we encourage trialists to focus on the experiences and needs of specific communities to ensure that their trials are genuinely inclusive.

The way that ethnic groups are categorised varies considerably depending on which country, government or institution is collecting the data. For this project, we have chosen to draw on the categories used by the UK's Office for National Statistics.

The Office for National Statistics has five main ethnic headings:

- 1.** White
- 2.** Mixed / Multiple ethnic groups
- 3.** Asian / Asian British
- 4.** Black / African / Caribbean / Black British
- 5.** Other ethnic groups

These five categories are broken down further:

- 1.** White
 - English / Welsh / Scottish / Northern Irish / British
 - Irish
 - Romani or Irish Traveller
 - Any other White background
- 2.** Mixed / Multiple ethnic groups
 - White and Black Caribbean
 - White and Black African
 - White and Asian
 - Any other Mixed / Multiple ethnic background
- 3.** Asian / Asian British
 - Indian
 - Pakistani
 - Bangladeshi
 - Chinese
 - Any other Asian background
- 4.** Black / African / Caribbean / Black British
 - African
 - Caribbean
 - Any other Black / African / Caribbean background
- 5.** Other ethnic group
 - Arab
 - Any other ethnic group

Not all trials will need to focus on the groups named in the expanded list, and some trials will need to focus on other groups that are not named here. The specific groups that trial teams need to concentrate on depends on

the aims and context of each trial. The critical point is that all trials need to consider and take account of the five main ethnic categories. However, which groups are focused on under those headings will be trial-dependent.

Trial teams should consider the five main ethnic categories but are free and should be encouraged to add more within-category granularity where this is useful in describing the target population. We do not want the tool to be used to stereotype ethnic groups. Groups of people with one shared characteristic (i.e. ethnicity) are not a monolith, and it is important to acknowledge that individual factors within groups play a crucial part. The important thing is that trialists are conscious of the way that they are designing and conducting trials, and that they put the people to whom the trial findings might apply at the forefront of their thoughts throughout the process.